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information and
inspiration to
individuals with
disabilities and
their families as
they direct their
own supports and
services



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Equity, Flexibility and Self-Direction: **The System of the Future is Here**

An Interview with Jim Smith

New Directions interviewed Jim Smith, former Director of DDD about Real Life Choices and its impact on the service system in New Jersey. Mr. Smith has since been appointed Deputy Commissioner of Human Services. Carol Grant is now Acting Director of DDD.

What will this systems change mean to families in New Jersey?

First, let me start with a little history. When the DDD system was set up, there were few options, few choices and little equity. DDD was like a paternalistic system – we would tell families what they could and could not have – but the big piece of the pie was the group home. We didn't want to create a new 'program;' wanted to look at the system as a whole, and find places for change. The changes will give more choices and more control to families and consumers, and bring more equity in the system.

"...people wanted to be more self-directed and have more say in their own care plans.."

How did DDD start the process?

We decided to survey people on our caseload to see what they wanted and needed. We also looked at what was happening across the country. What we found out was that folks wanted more options, to be more self- directed and to have more say in care plans.

What did you find when you surveyed people on the group home waiting list?

We always assumed that for most people, the "Pot of Gold" at end of rainbow was a group home. What we found out was that the vast majority of the folks on the waiting list wanted to stay at home, but needed an array of supports and services to do so. As we got deeper into the waiting list and surveyed parents who were not up in age, we saw that people were actually declining the offer of a group home placement. In fact, 25% to 30% of the folks we would approach for a group home placement would turn us down – consistently – year after year. They would say, "We are not ready yet." I believe they were seeing the waiting list as an insurance policy for the future.

What did you do with the information you gathered?

For one of the first times in the history of the Division, we began by involving people at the front end of this. We started to work with consumers and families to develop more

continues on page 3

Joshua: *From institutionalized to full participation*

Joshua Golden, 21-years old, is living proof of how a strong will and a determined family spirit can turn child institutionalization into adult self-actualization.

Joshua was born with Angelman Syndrome, which resulted in cognitive impairments and a difficult to control seizure disorder. His health issues mean that he must have others around him 24-hours a day to help him as needed. Joshua's significant challenges forced his family to place him in an institution when he was a child because that was the only way the state would dedicate funds to his care. He and his family hated this arrangement.

Joshua is a man who likes order and consistency in his life. He loved living with his family and the family home. He did not like living in facilities or group homes. He makes friends, works to keep them, and is an integral part of his family. Joshua's parents, sister and friends help Joshua solidify his life around his core desires to live near his family and friends. They created a micro-board or "self-directed support corporation" to manage Joshua's resources and entitlements and to put the support system in place to allow Joshua to live the life he wants.

The family knew Joshua liked the family home, so when Joshua became an adult, his parents and sister moved out and Joshua took over the house. His friends also acted as his caregivers and family members covered when lack of resources or

staffing leaves holes. Joshua is a core member of his micro-board and all board activities are directed to making Joshua's dreams come true.

"...Joshua was born into a service system that did not value independence and personal choice...

He is living proof of how a strong will and a determined family spirit can turn child institutionalization into adult self-actualization..."

Joshua's unique medical needs have required him to spend a great deal of time at his local hospital. He gets along well with his medical treatment team and knows so many people at the hospital that one might say the hospital is Joshua's second community. Even when medical attention hasn't been an issue, Joshua still wanted to visit his hospital friends. Joshua's micro-board understood that Joshua had formed the second community and helped Joshua develop a business within the hospital to provide individual support to various hospital staff. If Dr. Smith needed

flowers for his wife or something picked up from the dry cleaners, Joshua took on the task. With his micro-board's help, Joshua now is the informal "concierge" of the hospital.

Joshua was born into a service system that did not value independence and personal choice. He was institutionalized as a result. He and his family have channeled his determination into creating a "Joshua-centered" service system that has resulted in a 15% reduction in state funds dedicated to his needs. He now leads an active and productive life centered on his choices and needs.

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Interview with Jim Smith

continued from the cover

options and more equity in the system. It was clear to us that not everybody has the same level of need. What we have developed is an assessment tool that divided people into levels based on need, and a customized plan that that the family develops with the assistance of our folks for planning – support coordinators.

RLC funds services and supports in the family home, but what about the issue of housing for people who cannot stay at home, or who prefer not to?

There will always be some folks who need residential services. RLC does not mean there will be no new residential services. We hope to expanded our capacity to provide housing in the community using vouchers. In fact, roughly 100 people are now using RLC funds in combination with housing vouchers to live outside the family home.

Families coming onto RLC receive traditional residential services, if it is determined that is what they need. During one of our family group orientations, we had two elderly families come in who clearly didn't have ability to maneuver the system. We realized as we got into the interview that they needed out-of-home residential services, and those services have been provided.

The issue of 'equity' in the service system has been at the forefront of many discussions. How is RLC more equitable?

In the past, some people got everything, others, nothing. RLC addresses this through the assessment process, allocating funds based on need. So far, we have been pretty close on the identification of levels – most families

"Our system change in New Jersey is young, but we will continue to follow the national trend toward more self-directed services."

can clearly see the needs of people are different. In fact, many families actually see the equity first –they can see why someone with fewer self care skills needs more help and resource than they might. We are serving people with a full range of needs in all four categories. We have approved budgets from \$14,000 to \$63,000 per person, depending on the need.

How is the systems change addressing the need for a more flexible system?

RLC provides flexibility, choice and individual budgets. In RLC, money is wrapped around the person, and funding is based on identified needs. There is flexibility that can help people in an emergency. Money can be used for job support, day supports and what ever else is needed. If the person's needs or situation changes, there is an opportunity to get more services.

What do you see in the future?

Our systems change in New Jersey is young. I think we will see it mature in three to five years, but we will continue to follow the national trend toward more self-direction on the part of families and consumers. By the end of this fiscal year, RLC will have touched the lives of 300 people.

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Jim Smith Appointed Deputy Commissioner

James W. Smith, Director of the Division of Developmental Disabilities (DDD), has been named Deputy Commissioner of the Department of Human Services. He will replace David Heins, who is retiring, effective August 1. DDD Deputy Director, Carol Grant will serve as acting DDD director.

"Jim has had an outstanding career in this department," said Commissioner James Davy. "There are few people who enjoy the recognition and respect Jim does both inside and outside the department."

Smith served as director of DDD since 2002. During his tenure, the division streamlined the process for developing group homes, launched Real Life Choices and maintained federal certification at all of the seven state-operated developmental centers. Smith worked with the Office of Special Education Programs and the Division of Vocational Rehabilitation to outreach to students who are transitioning from school to adult life, working to ensure that everyone who wants services has an opportunity to get them.

"I'm leaving Developmental Disabilities with something of a heavy heart. During my time there I got to know and respect not only staff, but also consumers, their families, the advocates and the providers," said Smith. "I know Commissioner Davy is bringing many new initiatives and a new perspective to the department and I'm looking forward to helping him in any way I can."

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